



Nevada Early Intervention Spring-Summer Family Newsletter

May-June 2015 Volume 5 No 3

Message from Part C's State Family Resource Coordinator, Information & Referral...

"Parents who have lived the experience of parenting a child with... health needs and have learned the hard way how to access services are a largely untapped high value/low cost resource... the overhead on their incredible experience and the trust they can engender among other families is likely to be modest compared to the high costs of traditional services". — Adapted from Peer Parents: A Solution to Extend Child Mental Health Services, Posted March 17, 2011, by Kimberly E. Hoagwood, Ph.D, Professor of Clinical Psychology in Psychiatry, Columbia University and Kelly J. Kelleher, MD, MPH, Director, Center for Innovation in Pediatric Practice, Research Institute, Nationwide Children's Hospital.

Dear Parents/Families,

Have you thought of getting more involved in your early intervention program? Would you like to "give back" to the program? Would you like to help another parent or child? Would you like to have input in local and state planning and policy decisions that affect young children with disabilities? There are lots of opportunities for you!

Your early intervention program may have a family support group or work

with an organization that does. This is a wonderful way to "give back" to the program.

Nevada's Early Intervention Interagency Coordinating Council (ICC) was set up to advise and assist Nevada in the development and implementation of a statewide system of early intervention services for young children with developmental delays or disabilities and their families. If you would like more information about meetings or how to submit public comments to the Council, please contact me.

If you have questions, contact me at: ProjectAssist@dhhs.nv.gov or 1-800-522-0066—Project ASSIST

Sincerely,
Dan Dinnell

P.S. We have a new Administrative Assistant in the office! And she has "Been there, done that!", See page 2.



Cheryl, Eric, and Dan

NEVADA'S EARLY INTERVENTION SERVICES

IDEA Part C Office
4126 Technology Way, Suite 100
Carson City, NV 89706
Office: (775) 687-0587
Fax: (775) 687-0599

Project ASSIST
1-800-522-0066

ProjectAssist@dhhs.nv.gov

****The Nevada Disabilities Conference 2015**

Early Bird Registration begins April 1st — See page 3.

*Web Address: <http://dhhs.nv.gov/Programs/IDEA/ProjectASSIST>

If you are interested in volunteer activities, the State ICC has a permanent **FAMILY SUPPORT RESOURCE SUBCOMMITTEE** (FSRS) that can always use parents and others who have a passion for supporting early intervention... Contact: ProjectAssist@dhhs.nv.gov

FREE.... Participation in the national **EARLY INTERVENTION FAMILY ALLIANCE (EIFA)** is open to *all interested* in supporting early intervention. . . **Keep informed! Obtain Answers! Impact Policies!**

The EARLY INTERVENTION FAMILY ALLIANCE is a national leadership organization dedicated to improving outcomes for infants and toddlers with disabilities and their families, open to all.

Members receive email alerts and updates on key early intervention topics and can join the **EIFA list serve** to participate in active discussions and share experiences. Web: www.eifamilyalliance.org

Been there, done that!

We have a new addition to the IDEA Part C Office, our new Administrative Assistant, Ellen Marquez, and we are very excited to have her on the IDEA Part C Office team. Her skills and perspective will be a tremendous asset to the office.

Hi, my name is Ellen Marquez. My husband, Rick, and I are the proud parents of four children. Rick has two boys, Ricky (24) and David (22), and I have a daughter, Heather (21). And together we have our daughter, Alysa (12). When Rick and I got together we discussed having another child. Since I was 37 at the time, the discussion centered on my age and the possibility of what could happen having a child at that time. We decided we wanted another child and we would deal with whatever happened.



One year later I was pregnant. Because of my concerns, my doctor sent me for an amniocentesis. I wanted everyone to be prepared just in case there was something wrong when she was born. At 5 $\frac{1}{2}$ months pregnant, I found out that my daughter would be born with Down Syndrome. I went through my boo hoo's and did my research on what Down Syndrome brings. There were so many unknowns, but I was anxious and excited for my baby girl.

On March 10, 2003, Alysa was born. The beautiful girl I knew she would be. On March 13th, we were given the news that she had a heart condition that needed to be repaired. What do we do to keep her? Surgery was the only option. So to Stanford we went. Seven days later, we brought home our baby girl.

As a parent you think you can teach your children everything. But, with a child with a disability, I felt I knew nothing. Do I teach her like I did my other daughter? Will she learn like other children? There was so much I didn't know. I contacted Early Intervention Services in Reno. Our Developmental Specialist (DS) came into our home and eased many of my fears. With her help and guidance Alysa flourished. I remember wanting Alysa to pull her feet up and play with them like other children do. Our DS suggested painting her toenails with red nail polish. I was so excited the first time she grabbed them and played with them. I did not think of painting a 5 month olds nails. She gave me bench marks for Alysa, but explained she will do it at her time, not my time. Every bench mark Alysa made was so exciting.

Now that Alysa is 12, we have Rural Regional Services keeping us on track. Even though our case worker is there for Alysa, she is my advocate and she makes sure that our family is doing well and Alysa is getting services. Most of Alysa's services come through the school district. When I have IEP meetings or something just doesn't seem right, my case worker is there assisting me. If there is something I don't understand, she explains it or gets the information for me. Together, we make sure that Alysa is getting the education she deserves. With the help of Early Intervention, Rural Regional Services and me advocating for my daughter, Alysa has become a wonderful student and young lady, liked and respected by her teachers and peers.

Ellen Marquez, Admin. Assistant II
IDEA Part C Office

A PARENT IS A CHILD'S BEST ADVOCATE, AND EVERYONE HAS THE ABILITY TO BECOME A STRONG ADVOCATE. HOWEVER, TO BECOME AN EFFECTIVE ADVOCATE, YOU MUST SPEND TIME PREPARING AND LEARNING IMPORTANT ADVOCACY SKILLS.

NEVADA Disabilities

CONFERENCE 2015

Break Barriers → Open Doors

— July 20-21, 2015 —

At the JA Nugget in Sparks, Nevada

Early Bird Registration begins April 1st — Get Registered Now!!!

The NEVADA DISABILITIES CONFERENCE is a major, statewide event that will provide a one stop platform for connecting to the resources, trainings, best practices and support for creating healthier lives for individuals with developmental disabilities, advocates, caregivers and families of children with special health care needs and the professionals who serve them including administrators, educators, and healthcare/service providers.

The NATIONAL ASSOCIATION OF COUNCILS ON DEVELOPMENTAL DISABILITIES will combine with the NEVADA DISABILITIES CONFERENCE, bringing national experts in the field of disability to our state.

This is a great opportunity for families and individuals affected by disabilities or special health care needs, administrators, healthcare professionals, educators, students, caregivers, advocates, policymakers, service providers to learn about various possible topics of interest, such as:

• **advocacy • Assistive Technology • early intervention • special education • futures planning • recreation • health & dental care • mental health • building community • family support • service supports • independent living • inclusion • transition • self-determination • respite • and more.**

***Early Bird Registration begins April 1 — For more information contact Family TIES Statewide at ndc2015@familytiesnv.org or (866) 326-8437 / www.familytiesnv.org**

WEBSITE ONLINE

Nvdisabilitiesconference.org

*This event provides a truly unique opportunity where people can attend educational breakout sessions relevant to their specific needs, interact with policymakers, network with others and learn about the wide range of services available in Nevada. **Plan on it!!!***



Get started!!! Plan ahead—check with your local support organizations... Sometimes there are resources available to help cover some or all of the costs of transportation, hotels, meals, and registration for families to be able to attend conferences...

A limited number of **scholarships** for parents and family members of children with disabilities are available on a first-come, first-served basis from the **NEVADA GOVERNOR'S COUNCIL ON DEVELOPMENTAL DISABILITIES** (NGCDD). Click on Projects & Activities where you can access the paperwork for the **Consumer Leadership Development Fund Applications**. Start early!!!

Interested individuals may apply for these scholarships through the Consumer Leadership Development Fund Application at: www.nevadaddcouncil.org/consumer-leadership-3/

Applicants must turn in the full and completed applications by **Friday, May 29th**. Applicants will be notified by Monday, June 15th if they are to receive scholarship funds. **For assistance** in completing this form, call 775-684-8619 or email: Jessica.banes@dhhs.nv.gov

****Scholarship recipients will have their registration fees paid directly by the NGCDD and be reimbursed at the GSA.gov rate after the conference for travel, hotel, and per diem costs [meals] not covered by the conference. The maximum reimbursement is \$500 per individual or \$750 per family.**

For more information visit their website at: www.nevadaddcouncil.org

One of the Great Conference Keynotes You Don't Want to Miss!

Robert Naseef, Ph.D., is the father of an adult son with autism, and has "a foot in each world" as a father and a professional. He received his doctoral degree in psychological studies from Temple University and has practiced for over 20 years as a psychologist. He has a full-time independent practice in Philadelphia, in psychology that specializes in working with families of children with autism and other disabilities or special needs.



Dr. Naseef has a broad background in both education and psychology, and was instrumental in developing a training package to foster parent-professional collaboration for the New Jersey Department of Education, Division of Special Education, and taught graduate courses at Antioch University in Philadelphia and Rider University in Lawrenceville, New Jersey. He served as field supervisor for doctoral students from Rutgers University Center for Applied Psychology. He was a faculty member at American Healthcare Institute where he taught courses in childhood mood, anxiety, and developmental disorders. He holds clinical privileges in psychology at Penn Behavioral Health, University of Pennsylvania Hospital, serves on the board of directors of the Center for Autism, and the professional advisory board of the Philadelphia Autism Center for Excellence.

In 2008, Robert Naseef was honored by "*Variety, the Children's Charity*" for his outstanding contributions over the past 20 years to the autism community.

He has published in scholarly journals and other publications including several books, "*Special Children, Challenged Parents: The Struggles and Rewards of Raising a Child With a Disability*", and "*Autism in the Family: Caring and Coping Together*". He is the co-editor with Dr. Cindy N. Ariel of *Voices from the Spectrum: Parents, Grandparents, Siblings, People with Autism, and Professionals Share Their Wisdom*". "*Living Along the Autism Spectrum*" is a DVD which features him with Stephen Shore and Dan Gottlieb.

Dr. Naseef has lectured nationally and internationally on issues related to family life with special needs and was invited as a key presenter at the 2014 World Autism Congress in Kuwait City. He has appeared on radio and television. He has a special interest and expertise in the psychology of men and fatherhood, and facilitates a "Google Hangout" called, "Guy Talk", hosted by AutismBrainstorm.org, where they discuss specific topics as an online resource to support fathers and strengthen families.

The Part C Family Newsletter has opportunities to suggest and share... You are invited to submit articles, share your story, or include your child in a Family Spotlight, with a photo. (All items are subject to editing and review.)

AWESOME!!! "Assistive Technology For All of Us!"

In an effort to expand their outreach, the *Down Syndrome Network of Northern Nevada*, with support from the Nevada Early Intervention Services' conferencing facility in Reno, has reached out to Elko and surrounding rural areas. A Family Support Group had been started in Elko thanks to the efforts of Janina Easley, and now strengthened with the help of Christine Riggi, and Amanda Merrill, Development Coordinator *Down Syndrome Network of Northern Nevada*. At their last get together, through video and teleconferencing, everyone was able to enjoy a great presentation on Guardianship by Mary Bryant from the Nevada Center on Excellence in Disabilities, with video and teleconference assistance.

The Family Support Group is for **ALL** of those out there **with any type of special needs** and their families. It is a great place to make new friends, for peer support, and to become a better advocate. A guest presenter gives a presentation on a different topic that impacts the disability community each month. Please bring the family and join us the first Thursday of each month from 5:45 to 7:30pm [except for Summer months activities or other special events] at Nevada's Early Intervention Services Office in Elko.

To RSVP contact Janina Easley at jfal84@yahoo.com. If you have questions, please visit our website at www.DSNNN.org or call 775-828-5153.

— Janina Easley, ICC Parent Representative

More Resources... More Information... More Opportunities...



These next two months we celebrate both "Mother's Day" & "Father's Day".

Take the time. Like any parent, when you find out your child has a disability the first thing you look for is information. You read books, do research on the internet, and ask questions. Never stop learning.

Families are a key part of the early childhood intervention team. However parents of children with disabilities daily face a daunting array of decisions in support of their children. Family caregiving involves medical, educational, emotional, and psychological support, both for the children with disabilities and for other family members (e.g., siblings).

One of the resources available to parents, professionals, educators, and staff working with young children with disabilities and their families is the Early Childhood Special Education Library located in the IDEA Part C Office. This library contains thousands of books, articles, videos and other materials regarding children, families, disabilities, parenting, grandparenting, sibling relationships, working as a team, and early intervention practices. This library is available for use statewide to families, service providers and educators; families can request materials through their service coordinator.

Check out some of the Library books/videos below. . .

Videos

"A Child with Special Needs" – DVD features families with special needs children who share their personal stories. Doctors, legal advisors, educators, and special needs workers also offer guidance and encouragement to help parents cope and become the best possible advocate for their child.

Books

"Building a Joyful Life with your Child who has Special Needs" — Considers the challenges of caring for children with physical, developmental and mental health disorders and proposes methods such as learning to see events through your child's own eyes, celebrating their strengths and achievements and recognizing how others can help your child.

"Uncommon Fathers: Reflections on Raising a Child With a Disability" — a moving collection of 19 essays by fathers with children of various ages and various special needs. This book gives voice to fathers who are often overlooked in the literature about families of children with special needs.

There is also a **"Guide for Dads"** available on the Project ASSIST web site at:

dhhs.nv.gov/Programs/IDEA/ProjectASSIST/Fathers/

For other titles — dhhs.nv.gov/Programs/IDEA/ProjectASSIST/Special-Ed-Library/

These library materials are available for use statewide. For more information, contact your service provider or coordinator. If you have questions or recommendations for the Library, please contact me at **Project ASSIST** toll free **1-800-522-0066** or ProjectAssist@dhhs.nv.gov

Social Security benefits for children with disabilities.

A child with a disability who is younger than 18 years of age may be eligible for Supplemental Security Income (SSI). Have a look at SSA's *Child Disability Starter Kit*, which includes a fact sheet on the application process, a child disability interview preparation checklist and a Medical and School Worksheet. In English & Spanish - http://www.ssa.gov/disability/disability_starter_kits_child_eng.htm



FREE – National Parks and Federal Recreational Lands Access Pass

This is a **lifetime** pass for **U.S. citizens/permanent residents with permanent disabilities**. Documentation is required to obtain the pass. The pass in most cases provides free access to, and use of, Federal recreation sites that charge an Entrance fee. The pass admits the pass holder and passengers in a non-commercial vehicle at per vehicle fee areas, and pass holder + 3 adults, not to exceed 4 adults, at per person fee areas (children under 16 are admitted free). **The pass can only be obtained in person at the park or from a participating Federal recreation site or office.**

For more information, visit... <http://store.usgs.gov/pass/access.html>

EARLY INTERVENTION PROGRAM ACTIVITIES OR EVENTS FOR FAMILIES AND FRIENDS

NORTHEASTERN NEVADA EARLY INTERVENTION SERVICES

* contact your **Developmental Specialist/Service Coordinator** for more information

⇒ Nevada Early Intervention Services—Elko:

- The **Family Support Group** is for **ALL** of those families out there **with children with any type of special needs**. Please bring the family and join us the first Thursday of each month from 5:45 to 7:30pm [except for Summer months activities or other special events] at Nevada's Early Intervention Services Office in Elko. To RSVP contact Janina Easley at jfal84@yahoo.com or call 775-828-5153.

NORTHWESTERN NEVADA EARLY INTERVENTION SERVICES

* contact your **Developmental Specialist/Service Coordinator** for more information

⇒ Advanced Pediatric Therapies—Reno:

- **Community Play groups** every 2nd & 4th Friday, each month at 10:30am. They will be in different locations depending on the weather so families should call to find out the location! 775-825-4744. Lots of fun games and activities for the kids.

⇒ Nevada Early Intervention Services—Reno:

- **Family Support Group**, open to all parents, sponsored by Down Syndrome Network of Northern Nevada & NEIS - The 1st Thursday each month [except for Summer months activities or other special events] 5:45 pm, at NEIS. Call 775-828-5159 or e-mail dsnninfo@gmail.com to R.S.V.P.
- **Family TIES** provides family support in filling out **Medicaid/SSI and other Social Services applications** every 2nd Monday from 10am-12noon at NEIS, by RSVP only! Please call 775-823-9500 to RSVP.
- **RAVE** will have **Respite Applications** available every 2nd Monday from 10am-12noon at NEIS.
- **Friends of Special Children** is looking for new board members to join their non-profit organization that supports families in Early Intervention. This non-profit has supported families at NEIS in so many ways both financially and physically. If you are interested in being a part of this great cause, contact Lori Schoen at 688-0379 or email: lschoen@health.nv.gov
- **Hands and Voices** meets at NEIS, usually the 4th Thursday of every other month on the "odd" months, at 6:00 pm. Contact 351-1959, or email: info@nvhandsandvoices.org

⇒ The Continuum—Reno:

- **Carousel Kids** is a licensed childcare specializing in early childhood education. We pride ourselves in being an inclusive childcare where all children are recognized for individuality and different abilities. We also offer an intergenerational experience where children interact with elders from Regenerations, our onsite adult day program. Call the childcare director for more information or to schedule a tour # (775) 829-4700.
- **Grandparents raising grandchildren with special needs — Support Group**, 3700 Grant Dr., Reno. First Thursday monthly, with free childcare on site. For more information call Amanda Aitchison at (775) 737-8756.

SOUTHERN NEVADA EARLY INTERVENTION SERVICES

* contact your **Developmental Specialist/Service Coordinator** for more information

⇒ Easter Seals Nevada—Las Vegas:

- **Playgroups** on Fridays. Come Join the Fun! For more information call or email Ella Philander, at 428-4335 or ella.philander@eastersealsnevada.org

⇒ ISS Baby Steps—Las Vegas:

- At the **Inspired Discoveries playgroup**, we welcome children who are between the ages of 0-3 years old and their families. We will explore & learn in an inclusive setting for all children, while growing together in sensory, gross motor, fine motor, cognitive, self-help, and socio-emotional skills. We also hope that by providing family to family connections, supports, and resources we can help empower and educate individuals and their families. Please join in on our fun, learning adventure!" Call: (702) 279-4174

⇒ Nevada Early Intervention Services—Las Vegas:

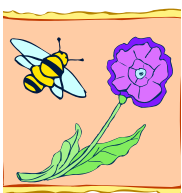
- **Parent meeting** for families of children (any age) with Prader Willi Syndrome, at NEIS. Contact Erica Magana (Bilingual) at 486-9265 emagana@adsd.nv.gov, or Shirley Farkas 486-9263 sfarkas@adsd.nv.gov

⇒ Positively Kids—Las Vegas:

- **Neo-Pediatric Clinic** — Do you have a child that was born before 37 weeks? Do you have concerns? If yes, call now to see our Neonatologist Dr. Abdulla. Phone: 702-262-0037

⇒ Therapy Management Group—Las Vegas:

- **Milagros Escondidos** family support group, last Thursday of the month, 6-8pm, at 6600 W. Charleston Blvd., Ste. 111
- TMG is partnering with Family to Family and conducting twice a week **inclusive developmental playgroups**. Contact: Sarah Petrocelli @ 340-5521 or spetrocelli@tmgnv.com
- **Mom's Planning Committee**—Meetings will be at TMG on the 3rd Saturday of the month. Email Martha at mestrada@tmgnv.com or call (702) 595-5437 X 205.



<http://dhhs.nv.gov/Programs/IDEA/ProjectASSIST>

Nevada's Central Directory website is filled with information and resources, including a "Links" page with all kinds of useful websites for information, and a Frequently Asked Questions page.

To receive the newsletter electronically and to make sure you don't miss out on useful information, please send your e-mail address to Dan Dinnell at ProjectAssist@dhhs.nv.gov

